



DEPARTMENT OF TRADE AND INDUSTRY
OFFICE OF SCIENCE AND TECHNOLOGY

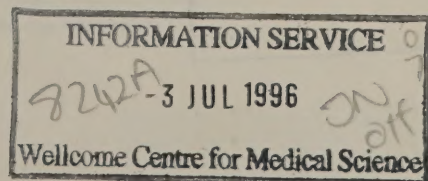
HUMAN GENETICS: THE GOVERNMENT'S RESPONSE

Government Response to the Third Report of
the House of Commons Select Committee on
Science and Technology
1995–96 Session

*Presented to Parliament by the President of the Board of Trade
by Command of Her Majesty
June 1996*

LONDON: HMSO
£2.00

Cm 3306



WELLCOME LIBRARY
P
8787



22501698641

HUMAN GENETICS: THE GOVERNMENT'S RESPONSE

GOVERNMENT RESPONSE TO THE REPORT BY THE HOUSE OF COMMONS SELECT COMMITTEE ON SCIENCE AND TECHNOLOGY

INTRODUCTION

1. The Government is grateful for the Select Committee's further report on Human Genetics¹. The Committee extended its Inquiry to allow consideration of the Government's response² to its initial report. This has provided the opportunity for a valuable dialogue between Government and the Committee, enabling each to clarify their position. Both the Secretary of State for Health, Mr Stephen Dorrell, and the Minister for Science and Technology, Mr Ian Taylor, gave oral evidence to the Committee during its further Inquiry.
2. The Government continues to share the Committee's views about the importance of human genetics and of retaining the UK's international standing within the genetic research community. Evidence of the Government's commitment to genetic research was set out in its previous response. The third Forward Look of Government-funded Science, Engineering and Technology (SET)³, published last month, shows how the Government is advancing its SET policies across a broad range of fronts, including in genetic science.
3. The Government also welcomes the Committee's acknowledgement of the extent of the activity already taking place in Government in response to the advance of genetic research. The Government's previous response specified a variety of mechanisms which allow the Government to respond to developments in genetics as they affect individual policy areas. The Government continues to believe that, with the addition of the new Advisory Committee on Genetic Testing (see paragraph 7 below), these mechanisms extend across the issues identified by the Committee in its earlier report.
4. As noted in the oral evidence given by Ministers to the Committee during its further Inquiry, there is a variety of existing mechanisms which facilitate coordination between these bodies. These include the Interdepartmental Group on Genetic Modification Technology (IGGMOT), an official level committee chaired by the Office of Science and Technology (OST). IGGMOT's role is to coordinate and develop cross-departmental policy on genetic modification technology, and to coordinate the presentation of that policy in the EU and in international fora.
5. The Government also places considerable emphasis on improving the public understanding of science, both as a whole and within particular fields. It is continuing with its major public understanding campaign, currently worth around £1.25m a year which culminates each year in National Science Week. The third such week was held from 15–24 March this year and was the largest yet with some 5,000 events across the UK. These included significant examples which focused either wholly or partly on advances in genetics or on the wider field of biotechnology. Last year, over 600,000 people attended events with millions more reached through television and newspaper involvement.

¹Human Genetics: The Government's Response, House of Commons Science and Technology Committee, Third Report Session 1995–96, HC231, HMSO

²Human Genetics: The Science and its Consequences, Government Response to the Third Report of the House of Commons Select Committee on Science and Technology, 1994–95 Session, Cm 3061, HMSO

³Forward Look of Government-funded Science, Engineering and Technology 1996, Cm 3257, HMSO

6. The Government believes that much of the strength of this campaign derives from its "bottom-up" approach, engaging the skills and enthusiasm of individual scientists, engineers and technologists. The Government believes it would be neither feasible nor desirable for such a campaign to be mounted by Government alone. However, the Government accepts the Committee's view that public confidence in scientific advance depends on knowledge about how issues are being handled within Government as well as education about the science involved.

USES OF GENETICS

7. In relation to healthcare, the Committee notes that many of its concerns about the responsible use of genetic science have now been allayed. The Committee welcomes the establishment of the Advisory Committee on Genetic Testing by the Department of Health, which will be chaired by Rev Dr John Polkinghorne, President of Queens' College, Cambridge. As noted in the Government's previous response, this new body will advise on the ethical, social and scientific aspects of genetic tests and will establish agreed standards for efficacy and product information to be met by manufacturers of genetic tests. The Advisory Committee will consider the use and potential use of tests, both in clinical practice and sales to the public. However, it will also draw health Ministers' attention to any issues which it believes other Government departments might wish to address, for example the broader implications of genetic testing for fields such as insurance and employment.

8. On insurance, the Government's previous response welcomed the dialogue between the Association of British Insurers (ABI) and leading geneticists with a view to identifying potential problems and exploring common ground on solutions. The Government undertook to keep in touch with developments and expressed the hope that there would be substantial progress within 12 months.

9. The Government has continued to maintain contact with the ABI and has discussed with them the prospects for the development of an industry-wide code of practice. The Government welcomes the Committee's view that such a code would be preferable to legislation on the grounds that it would be more adaptable to developments in genetic science. The Government understands that the ABI has been promoting careful consideration of this matter among its members and that an announcement can be expected shortly. The Government believes that the ABI should respond rapidly.

10. The Committee also makes further comments on the uses of genetics in relation to patenting and employment. In each case, the Committee notes the machinery already in place but considers that an independent, non-technical body would assist in reassuring the public that the implications of genetic science were being properly addressed.

A NEW OVERVIEW BODY

11. The Committee restates its view that, notwithstanding the range of existing bodies, there is the need for a further group to take a broad view and to provide a clearer focus for the public as a source of impartial and open advice on genetic matters. The potential merits for such a group were helpfully explored between Ministers and the Committee during its further Inquiry. The Government notes that the Committee is not calling for a body with any immediate statutory or regulatory role, though the Committee sees the potential for such a role to develop over time.

12. The Government continues to believe that it would not be practical to establish a regulatory body which would take over the functions already being performed by existing, more specialist technical committees. The breadth and nature of those functions is such that it is difficult to see how such a body could avoid becoming unwieldy and bureaucratic. This would be particularly inappropriate in a field where the science is advancing rapidly, requiring flexibility of response.

13. In the course of its dialogue with the Committee, however, the Government undertook to review the case for an overview body whose main functions would be to take a trans-departmental view of developments in human genetics and to foster public confidence in the new science. In the light of this consideration and the further evidence provided to the Committee, the Government has decided to establish a new Human Genetics Advisory Commission.

14. The Advisory Commission will be a strategic group of eminent independent members whose task will be: to review scientific progress at the frontiers of human genetics; to report on issues that can be expected to have broad social, ethical and/or economic consequences, for example in relation to public health, insurance, patents and employment; and to advise on ways to build confidence in, and understanding of, the new genetics. Terms of reference are provided at Annex 1.

15. The Advisory Commission will report to Ministers periodically and it will also be open to the Government to seek its advice on particular issues. Reports will be published. In keeping with its broader public role, the Advisory Commission will be asked to give early consideration to how best to make itself open to views from the public. It will maintain contact with non-Governmental groups with an interest in the field, such as the Nuffield Council on Bioethics.

16. Members of the Advisory Commission will be chosen on their own merits but will represent between them informed opinion on developments in the science of human genetics as well as social, health, ethical and economic implications. Members might include, for example, senior figures from genetic research, industry and the public health sector. In view of its role in relation to public confidence, one or more members with experience of the media might be appropriate. It will be important that the Advisory Commission, as a whole, is seen to be able to take a broad perspective on the implications of genetics, as distinct from the interests of particular groups.

17. The Committee considers that cross-membership between a new body to oversee genetics and existing committees would give the body a valuable source of expertise. The Government agrees that there needs to be a relationship between the new Advisory Commission and other existing, more technical groups. The aim should be to aid communication between groups doing essentially different types of work, but at the same time avoiding any strict hierarchical relationship. Decisions on membership of the new body will be announced as soon as possible but, meanwhile, the Government considers that there is a *prima facie* case for including in it the Chairmen of the Gene Therapy Advisory Committee and the new Advisory Committee on Genetic Testing.

18. In view of its strategic role, the work of the Advisory Commission will be of interest to a number of departments, though primarily to the health and industry departments. It will therefore report formally to health and industry Ministers, but other parts of Government will be kept in touch through OST's trans-departmental machinery. The Chief Scientific Adviser and the Chief Medical Officer will take a close interest in its work. A joint secretariat will be provided by the Office of Science and Technology and the Department of Health.

19. The Government has noted the Committee's proposal that there should be a debate about these matters on the floor of the House. Open debate on the various issues raised by genetic science will be important in promoting confidence. The Government agrees with the Committee that it will be desirable to debate the issues raised by advances in human genetics in Parliament. This should take place as soon as Parliamentary time allows.

CONCLUSION

20. Advances in human genetics promise many benefits for humankind and the UK is well placed to capitalise on these, both in terms of improved quality of life and wealth creation. However, the Government agrees with the Committee's view that public confidence needs to advance at a pace which reflects that of scientific discovery. The Government believes that the new Human Genetics Advisory Commission will address the issues raised by the Select Committee in a way which maintains essential flexibility in this fast-moving field.

HUMAN GENETICS ADVISORY COMMISSION

TERMS OF REFERENCE

The Human Genetics Advisory Commission will be a strategic group of eminent independent members which will:

- i. keep under review scientific progress at the frontiers of human genetics and related fields;
- ii. report on issues arising from new developments in human genetics that can be expected to have wider social, ethical and/or economic consequences, for example in relation to public health, insurance, patents and employment;
- iii. advise on ways to build public confidence in, and understanding of, the new genetics.

The Advisory Commission will report to Ministers periodically; reports will be published. It will establish contact with people in different sectors in the United Kingdom and will keep in touch with public views on human genetics. It will also keep abreast of developments in other countries.



Published by HMSO and available from:

HMSO Publications Centre

(Mail, fax and telephone orders only)

PO Box 276, London SW8 5DT

Telephone orders 0171-873 9090

General enquiries 0171-873 0011

(queuing system in operation for both numbers)

Fax orders 0171-873 8200

HMSO Bookshops

49 High Holborn, London WC1V 6HB

0171-873 0011 Fax 0171-831 1326 (counter service only)

68-69 Bull Street, Birmingham B4 6AD

0121-236 9696 Fax 0121-236 9699

33 Wine Street, Bristol BS1 2BQ

0117-926 4306 Fax 0117 9294515

9-21 Princess Street, Manchester M60 8AS

0161-834 7201 Fax 0161-833 0634

16 Arthur Street, Belfast BT1 4GD

01232 238451 Fax 01232 235401

71 Lothian Road, Edinburgh EH3 9AZ

0131-228 4181 Fax 0131-229 2734

The HMSO Oriel Bookshop,

The Friary, Cardiff CF1 4AA

01222 395548 Fax 01222 384347

HMSO's Accredited Agents

(see Yellow Pages)

and through good booksellers

ISBN 0-10-133062-6



9 780101 330626